Case study

UCB shows mid-size pharma can be big on transparency

In most industries, UCB would be considered a big player. The Belgian-born company has a presence in 40 countries and posted global revenues of €3.3 billion in 2014. In its field, UCB is a mid-sized biopharma operation specialising in medicines for serious diseases in immunology and neurology.

However, when opportunities to be in the vanguard arise, UCB has a record of stepping forward. And so it was when momentum gathered behind calls for greater openness on clinical study data. In 2014, UCB was the first mid-size pharma company to join other pharmaceutical companies on a custom-designed website, Clinical Study Data Request (CSDR), which manages requests for anonymised data. This system now supports requests for anonymised data from Astellas, Bayer, Boehringer Ingelheim, Eisai, GSK, Lilly, Novartis, Roche, Sanofi, Takeda, UCB and ViiV Healthcare.

The project gives researchers access to anonymised data from clinical studies, sparking new lines of medical research and avoiding duplication of effort by scientists. The project complements the material made available by UCB through UCB website, ClinicalTrials.gov and TransCelerate's knowledge vault.

For Catherine Bégard, Senior Director, Head of Information Intelligence & Integrity, UCB's role in the Clinical Study Data Request platform is a natural step given the company's commitment to openness and its ambition to create more value for patients and ultimately allow them to live the lives they choose.

"We want to share our study data with researchers for scientific purposes. As long as they are qualified to analyse the data appropriately we believe this ultimately benefits patients," says Catherine.

UCB has received four research proposals through the CSDR system since going live late last year. Two were from a research team at a top US university and related to Parkinson's disease therapy; another was for one of UCB's epilepsy compounds; and the fourth was for data from rheumatoid arthritis clinical studies. A single research proposal can cover several clinical studies so a substantial investment of time is required to meet demand.

One additional enquiry from a Clinical Research Organisation (CRO) was received by multiple sponsors. This CRO sought to use datasets for staff training. This request was declined as it fell outside the requirement to use the data for scientific purposes.

For researchers, the beauty of the system is that they can request access to anonymised data from clinical studies run by several companies. Many companies also use the same technology solution for sharing the anonymised data with the researcher, in which these data are shared in an online 'room'. A ‘room’ is created for each research proposal, so anonymised data from multiple companies are loaded into the same room if they are part of the same proposal. Researchers are given a ‘key’ (a password) to access their room which expires after one year. If they need more time, all they have to do is ask.

Liz Roberts, Director, Global Lead Transparency and Data Sharing, has been at the coalface of the project. "From the start this has been a real adventure as we were moving through unchartered territory but the experience so far has been extremely positive."

She says that other companies have been supportive and UCB's size has been an asset as it allows for greater flexibility. Patients, health professionals and others also take a positive

view of the company's efforts. "The feedback has been overwhelmingly positive, and it really encourages us moving forward on this journey."